

### Activity Report 2012

#### **Structure and development**

There is now a new board which met in Hebertshausen. There were elections and division of task. The outcomes of those elections were a new president Rick Pasman; a new vice-president Caroline van Heesewijk; a new secretary Doris Lösch and the new members Cindy de Klerk, Ton Schouten; Jake Freimark. We also have a treasurer Nigel Barrett.

There were 4 new families, 2 German families; 1 UK family and one French family. We welcome the new families in our network.

#### **Homepage**

[www.chromosome11.eu](http://www.chromosome11.eu)

Work on our homepage is continued. Translations need to be continued and we would like to improve on updates. However, also in this case, time is critical.

#### **Finances**

##### **Financial Support**

We very much appreciate and **sincerely thank** the following persons/institutions for their financial support:

- Family Feger
- GKV – Bund der deutschen Krankenkassen
- Family Disteli
- Family Keiser
- Eurordis
- Families Barrett and McLean
- Family Böller
- Family O'Byrne

#### **Short Report 2012**

Fortunately, we again received many donations from our members, their friends and relatives: over EUR 4,000 from 6 private donors!

Additionally we received another generous donation of EUR 2,500 from "GKV-Bund der Deutschen Krankenkassen" (German national association of statutory health insurance funds) and Eurordis made 2 separate donations totaling EUR 3,600. Taken together with the members' fees, our total income was just over EUR 11,000.

As with other years without a conference, our costs are relatively low so that part of our income can be set aside for future conferences. Last year our costs amounted to EUR 7,400, of which EUR 1,400 was used for participating in meetings of international organizations in our subject area (e.g. Eurordis). Traveling and subsistence costs of the board members for Board meetings amounted to EUR 2,500. In total we were able to save almost EUR 3,000 towards the next conference.

Therefore, our cash resources at the year end were almost EUR 36,000, of which EUR 21,000 are already reserved for the 2014 conference.

At this point, on behalf of The Board, I would like to sincerely thank all donors for their generosity. They allow our Network to continue to support families with a chromosome 11 child. THANK YOU!

Best wishes  
Nigel, Treasurer

#### **Membership and Cooperation**

Arne Eiwien and Caroline van Heesewijk visited the **European Conference for Rare Diseases**, which was organized by **EURORDIS**, in Brussels, Belgium, from 23-25 May 2012.

<http://www.eurordis.org/news/execute-summary-european-conference-rare-diseases-orphan-products-out>

The day before the conference, a meeting of **EUROCHROMNET** took place in Brussels. EUROCHROMNET is an affiliation of and for organizations for people affected by rare chromosome disorders and its main purpose it aimed at exchanging information and promoting cooperation.

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The Board sincerely thanks everybody who supported our Network actively, morally and/or financially in 2012!

The Board  
Leusden, the Netherlands 2012